Public Consultative Forum on Adaptive Communications Technology

Sponsored By

Decade of Disabled Persons Office
Province of Manitoba

THE UN DECADE OF DISABLED PERSONS IN MANITOBA

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Manitoba

Public Consultative Forum on Adaptive Communications Technology

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Public Advisory Forum
Adaptive Communication Technologies

Introduction and Executive Summary

This consultative forum on new communication technologies was sponsored by the Decade of Disabled Persons office, Province of Manitoba. It was held on the evening of November 1st in the auditorium of the Canadian Institute of Industrial Technology in Winnipeg. The purpose of this event was to create the opportunity whereby groups and individuals with an interest could make their views known concerning adaptive communication technologies. Those in attendance primarily represented consumer advocacy and self help organizations, and service providers and their associations. Several provincial civil servants were also present as observers. Verbal presentations were received from a total of eight organizations, three of whom provided supplementary written submissions (see attached appendices). In order of their appearance, presenters were:

- Manitoba Society of Occupational Therapists/Association of Occupational Therapists of Manitoba – Laurie Ringaert
- Society for Manitobans with Disabilities/Rehabilitation Centre for Children – Nigel Baseley and Art Quanbury
- Manitoba League of the Physically Handicapped – Terry Beeman
- Manitoba Speech and Hearing Association – Margaret Ellis
- Association for Community Living – David Wetherow
- Independent Living Resource Centre – Allan Simpson
- People in Equal Participation – Theresa Ducharme
- Cerebral Palsy Association – Nan Colledge

There were significant areas of agreement among the presenters concerning a basic rationale for putting into place and operating a government initiative to fund alternative communication devices. Important component parts for such a program were also detailed. Speakers in attendance made the following recommendations:

> The ability to communicate should be considered a universal right of all individuals. It is unacceptable for people to be limited in their communication because of a lack of resources or access to existing equipment.
>
> Therefore, service delivery programs must be broadly based and address themselves to both providing equipment and delivering required support to the potential user.
>
> A mechanism must be in place for repair and maintenance of various types of adaptive communications equipment, and 'loaners' must be available when needed on a temporary basis. The opportunity for users to try equipment prior to purchase must also exist.

Augmentative communication devices should not be segregated from other equipment in a delivery program. Government must consider such equipment in a total program with other specialized equipment as one is often dependent on the other.

Government must take a greater responsibility for improving the coordination of existing services relating to adaptive communication devices, in order to maximize their effectiveness.

Options ranging from high tech to low tech, and from a variety of manufacturer should be made available.

The Departments of Family Services, Health and Education and Training should work in collaboration to develop policies and a funding mechanism for adaptive communication devices.

Any government initiatives related to the provision of adaptive communication technologies must be equitably directed to both rural and urban clientele.

Adequate opportunities for all interested parties to make their viewpoints known must be ensured as policy and funding criteria are established vis-à-vis adaptive communication devices.

While those wishing to be heard articulated many common observations and ideas, two different conceptions emerged about the philosophy which should properly underlie a program designed to enhance access to alternative communication devices. These two differing trends of thought can best be summarized as follows:

Professional Model

Government should establish or fund a speech enhancement program in which a multi-disciplinary team of professionals is integrally involved in order to determine the selection, availability and appropriate application of adaptive communication technologies.

Self-Help/Consumer Model

Government should (similarly) establish or fund a program to improve the availability of adaptive communications devices. However, such resources should place less emphasis on the role of professionals and offer direct and universal access to potential users. Individual user should ultimately decide on the appropriateness and applicability of such technologies.

Public Consultative Forum

New Communication Technologies

The Forum began at 8:00 p.m. with Jim Derksen, Coordinator, Decade of Disabled Persons, Province of Manitoba, extending a welcome to those in attendance. The proceedings were videotaped for future telecast on cable systems throughout the province. Recognition was extended to Keith Allan for taking major responsibility for organizing the event, and to Deborah Bach and Yolande Matchett for their involvement during the evening.

The order of participant presentation was established, as follows:

- Manitoba Society of Occupational Therapists/Association of Occupational Therapists of Manitoba, Laurie Ringaert
- Society for Manitobans with Disabilities/Rehabilitation Centre for Children, Nigel Baseley and Art Quanbury
- Manitoba League of the Physically Handicapped, Terry Beeman
- Manitoba Speech and Hearing Association, Margaret Ellis
- Association for Community Living (Winnipeg), Dave Wetherow
- Independent Living Resource Centre, Allan Simpson
- People in Equal Participation, Theresa Ducharme

Manitoba Society of Occupational Therapists/ The Association of Occupational Therapists of Manitoba

Support was expressed for the concept of government funding for technical devices. Manitoba has lagged behind other jurisdictions in this area. Several recommendations were presented which it was felt would help protect the consumer. These are summarized as follows:

1. Assessment and treatment should involve a multi-disciplinary team.
2. A range of options should be made available from low tech to high tech, and from a variety of manufacturers.
3. A system must be in place for maintenance of equipment, and 'loaners' must be available while equipment is under repair since this device is vital to the individual's communication ability.
4. There should be a facility where various types of equipment can be available for assessment and loan prior to purchase. Consideration should be made regarding tying in to the Canadian Aging and Rehabilitation Product Development Centre in conjunction with the Independent Living Product Display Centre so as not to duplicate services. As well, this central concept will allow for product and program evaluation. Such a coordinated program will also allow the opportunity for professional upgrading since the field of advanced rehab technology is relatively new and products are constantly changing. This will provide more quality service delivery to the consumer.

5. There should be developed a community and rural outreach program for team members to visit people in their home, work, or school environment as specific adaptations may be required for these environments. Some people are unable to travel due to medical restrictions.

6. Augmentative communication devices should not be separated from other available technology in this proposed program. The Government must consider wheelchair seating systems, Environmental Control systems, etc. in a total program since often one is reliant on the other.

7. Prior to setting up a program, the Government review similar programs already in place such as the ADP program in Ontario. Such questions as – How much money? How is it coordinated? Costs not only involve actual purchase of the device, but also include various therapists' fees, maintenance, inventory control, etc.

There are severe penalties which our society attaches to disabilities associated with expressive communication. Such communication disorders affect both children and adults. Persons affected have the right to assessment and training in alternative means of communication. A technical communication device is only one possible solution. Often the use of 'fundamental rehab technologies' is the preferred option.

There are prerequisites to the use of augmentative communications devices which must be addressed before one considers the use of such technology. The range of technical options is great, and each user must be assessed wholistically to determine which option is best. It is not the case that the more advanced technology always provides the best solution. Even when the use of a high tech device is warranted, it requires the development of specialized skills in order that the user can take full advantage of it. This often takes the involvement of a multi-disciplinary team of professionals.

The Occupational Therapist takes a wholistic approach in the assessment of an individual. The OT works in cooperation with a multi-disciplinary team. The OT is particularly involved in the assessment of a seating system. This must in turn be compatible with the communication system. The OT in collaboration with the Speech Pathologist is involved in training the client in the use of the system.

Society for Manitobans With Disabilities and the Rehabilitation Hospital for Children

Computer technology was identified as an exciting development which increasingly will allow disabled persons who are dependent today to be independent in the future. A direct result of this enhanced independence is likely to be a decrease in the costs of support services such as medical and respite care.

Two areas were discussed in the introduction: 1) Augmentative or Alternative Communication (AAC). This covers a very broad range of options ranging from high tech to low tech. 2) Need for Service is becoming much more recognized in this province and beyond. With increasing advances in medical technology, more high risk new-borns are being saved and a greater number of 'head injured' trauma victims are surviving. Among these two groups in particular, there is and will be an increasing need for the deployment of AAC.

Issues

AAC requires a multi-disciplinary team of professional staff. Because of this approach, a high level of coordination and communication between the members of the team is necessary. At the same time there must be coordination with those involved at the working level, including the client.

Individualization of service planning is necessary because of the diverse abilities and circumstances of each user. There is no 'black box' solution which will work for all. The user and those in his/her environment must be trained.

The ability to communicate should be treated as a universal right of all individuals. Thus, service delivery programs must be broadly based and include both rural and urban situations, a wide range of age groups and different communication settings. Delivery programs must address themselves to the provision of a wide range of low and more expensive high tech equipment, and also to planning, training and servicing, taking into account differing circumstances.

Training is a multi-faceted issue, involving the range of professional staff, the user, and a 'facilitator' who is someone close to the user.

Support services must be in place whereby the equipment can be routinely maintained and repaired as needed. Access is required to back up and loaner systems, and alternate systems as warranted. The mechanisms must be in place for routine and ongoing modifications to the communications system. These needs must be built into the AAC program.

The roles of the two agencies represented were eluded to, and are outlined in some detail in the written report provided (see APPENDIX B).

Recommendations

1. It is recommended that the Departments of Family Services, Health and Education and Training work closely together to develop policies and a funding mechanism for AAC initiatives.

2. It is recommended that the government develops policies and funding procedures that incorporate both the equipment aspect of augmentative/alternative communication systems as well as the programming related needs (individual assessment, program plans, intervention strategies).

   Policies and procedures should also provide for continued follow-up/adjustment to the AAC systems provided to individuals.

3. There are already a number of service providers, associated with various agencies and including various teams of professionals, providing some AAC service to a variety of user groups. This activity needs to be coordinated to take advantage of existing experience and to strengthen the overall provision of AAC services.

   It is important to identify and build on the strengths of the present service systems and not introduce initiatives which result in further fragmentation.

4. There needs to be a balance between any funding for equipment and funding for staff and facilities to support the other components of a service program including evaluation, assessment, training, follow-up.

5. It is important that any Government initiatives include the needs of people with communication impairments who live in the rural regions of the province as well as those who live in Winnipeg.

Manitoba League of the Physically Handicapped (MLPH)

The representative for the MLPH began by indicating that he was 'taken back a bit' by some of the comments made by those who preceded him. His concern revolved around the perception that the consumer had not been given proper status in some of the presentations from service providers. It is the consumer for whom these technologies are being done. It is thus the consumer who must be given the prime consideration in this process.

The provision of augmentative communication technology should be a 'no fault' service wherein the consumer is provided the desired technology without undo conditions or financial burdens being attached.

Manitoba Speech and Hearing Association (MSHA)

The Manitoba Speech and Hearing Association is a professional association of speech pathologists and audiologists. In the experience of the association, augmentative communication devices (ACDs) can be very liberating. ACDs also often have utilities for accessing computers, environmental controls, etc.

ACDs are high tech devices. They are very expensive. At the present time, Manitoba has very little public policy with respect to their prescription and funding. When the support teams working on behalf of disabled clients wish to try out such a device, they must search long and hard for funding. Each department and agency has in place criteria which restrict the availability of monies for ACDs.

Public policy regarding funding of augmentative communication is needed. Models of service delivery exist in Ontario and Alberta, and should be examined by Manitoba. Questions of funding trigger a range of other quality of service issues. A support team must be able to provide for all aspects of augmentative communication. Support teams are now only partially in place in some Manitoba settings.

Steps must be taken to ensure that the ACD offers the best potential for the client. Presently, there are about 300 new devices and software on the market each year. It is difficult to keep up with developments.

Supplying an ACD at an inappropriate point in time may do significant harm insomuch as it may result in rejection of the idea at a later date when the client's needs may be well met by an augmentative communication device. Needs studies with adherence to guidelines of utility for the non-verbal person are needed.

Adequate training programs must be put in place. Such programs must begin long before the acquisition of the device, and in the setting in which it will be used.

There next followed a detailed account of the regime which should be followed in preparation for the matching of some form of augmentative communication

technology with a particular client. This may be reviewed in full in the attached written submission (see APPENDIX C).

We must avoid the errors which can occur if sufficient care is not taken in the process of making ACDs available to prospective clients. The benefits of funding policies which contain stringent criteria is that they can be used as a vehicle for ensuring that the interests of the non-speaking population are addressed.

The Manitoba Speech and Hearing Association is advocating that government develop policies and programs regarding ACDs and that the process include representatives from the non-verbal population, advocacy groups, parents, professional associations and the various government departments who are involved in serving the non-verbal population.

Association for Community Living (Wpg)

The Association for Community Living (ACL) presentation began by focusing on one policy issue: The idea that access to effective communication systems must be a fundamental entitlement of all persons because it has a fundamental impact on the way we develop, the way we are understood and are known by those with whom we associate.

We must do whatever we can do to make needed equipment, information, and technical support available to persons who have been locked in isolation for too long by their inability to communicate effectively.

A fundamental commitment must be made to render the means available for all persons in need of augmentative communications technology to have access to it without having to 'wait in line'. This will only occur when we make the decision that such access is a fundamental entitlement, like mobility. When this occurs, we will have then made a monumental step forward; especially in the area of services to children.

It was noted that the issue of 'fragmentation' had been discussed previously in the Forum. This fragmentation is not necessarily a disadvantage. The question was raised as to how many persons are bothered by the fact that the food system is 'fragmented'. Fragmentation was equated, by the speaker, with increased ability of the consumer to choose.

The ACL indicated that they are trying to promote such exposure to a range of equipment options through an ACL initiative called the "Open Access Network" about which information was made available at the Forum. Details can also be obtained from the Association for Community Living – Wpg.

Independent Living Resource Centre

Allan Simpson, representing the Independent living Resource Centre, (ILRC) endorsed the Public Forum method of consulting the community. The ILRC is challenged constantly to look at means whereby consumers can achieve their maximum independence in the community. The ILRC's concept of independence is to allow for maximum input from consumers into the development, planning, and evaluation process as it relates to ACD systems.

There are a number of key elements which make up full independent living with respect to the area of concern being discussed. These include knowledge, exposure, experience, input, evaluation and ultimately consumer choice.

The speaker expressed concern about the primacy of the professional in the process of making augmentative communication devices available. He sees politicians as possibly being dissuaded from giving priority to the purchase of such equipment for trial use because of the perceived costs associated with the professional component. The value of consumer input into government policy must be emphasized.

Within this province, concept of universal entitlement is applied in regard to wheelchair provision and maintenance. This concept must be expanded to include new communication technologies that enable persons who could potentially benefit from such devices, the opportunity to have them.

Beyond the objective criteria used to measure the value of an ACD for a particular individual, one must also consider the more subjective benefits (such as increased self confidence) which can arise from a user having the opportunity to try out and experiment with such augmentative communications technology. Government must recognize the legitimacy of the investment required to allow for such 'trial and error' exposure.

Often the use of ACDs requires some modification before they can be used by a specific individual. However, there is currently a shortage of staff and funding for the employment of staff who are expert in making these adaptations. The prompt availability of such expertise is crucial. As such, government must commit sufficient resources to ensure this service.

As policy and funding criteria are established, it is important that all parties concerned with the process have opportunities like this Forum (and other input mechanisms) to make known their perspectives. Non-verbal persons themselves should be encouraged to participate in such undertakings through the presentation of tier views and experiences.

People in Equal Participation (PEP)

The speaker complimented all participants on their presentations, and asked that a copy of each of these be sent to PEP. She recognized the role of the interpreters and emphasized the need for all of us to 'hear' one another.

Persons with disabilities are reliant on adequate levels of required service in order to be able to function effectively in society. Many of these service delivery systems are fragmented and very inadequate. This can be frightening.

The seminar tonight is of value in that it has given people the opportunity to see the choices of communication technology that are available. When communication is lost, it is frightening and potentially dangerous to the persons involved. Systems must be improved and staff training must be assured in order to make certain the communication does not break down. We must all work together to achieve that result.

At this point in the proceedings, Mr. Derksen invited participation from any additional persons who wished to be heard. He particularly expressed an

interest in hearing from individuals requiring the use of augmentative communication technology, who wished to address the Forum.

Cerebral Palsy Association (CPA)

Cerebral Palsy (CP) is one of the major conditions which can render people non-verbal. The speaker asserted that it is unacceptable to have persons who are limited to communicating with only three or four people because of lack of access to appropriate communications technology. Neither is it acceptable to have to secure funding for needed devices by making 'pitches' to service organizations on behalf of 'exceptional' individuals.

Communication is not an optional extra. It is a fundamental right, in the same way as education and mobility are fundamental rights.

At this point, Mr. Derksen thanked the participants and audience for their attendance. He indicated that the Decade of Disabled Persons office would appreciate receiving written copies of the presentations delivered during the evening. These have been attached as appendices to this document. The Forum on Augmentative Communications Technology was adjourned at 9:35 p.m.

APPENDIX A

MSOT Manitoba Society of Occupational Therapists

The Manitoba Society of Occupational Therapists

and

The Association of Occupational Therapists of Manitoba

Presentation

to

The Government of Manitoba

Provision of Augmentative Communication Technology In Manitoba

November 1989

This position paper was developed in response to the announcement of a public consultative form sponsored by the Government of Manitoba – Decade of Disabled Persons initiative, regarding New Communications Technology. Interested persons and organizations were invited to make their views known regarding the application and availability of 'speech generating' technology at a meeting held at the Canadian Institute of Industrial Technology, 435 Ellice Avenue, Winnipeg, Manitoba, November 1, 1989, 8:00 – 10:00 p.m.

I would like to thank the following people who assisted me with this paper:

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MSOT/AOTM Presentation to Government on Provision of Augmentative Communication Technology in Manitoba

Manitoba Government Involvement in Provision of Technical Devices

The Manitoba Society of Occupational Therapists and the Association of Occupational Therapists of Manitoba support the concept of Government funding for technical devices for disabled adults and children. Communication is a fundamental activity. Many individuals require a device to aid their communication. Manitoba has lagged behind other jurisdictions in this area. We do, however, have several recommendations which we feel will help protect the consumer:

1) Assessment and treatment should involve a multidisciplinary team.

2) A range of options should be made available from low tech to high tech, and from a variety of manufacturers.

3) A system must be in place for maintenance of equipment and 'loaners' must be available while equipment is under repair since this device is vital to the individual's communication ability.

4) There should be a facility where various types of equipment can be available for assessment and loan prior to purchase. Consideration should be made regarding tying in to the Canadian Aging & Rehabilitation Product Development Centre in conjunction with the Independent Living Product Display Centre so as not to duplicate services. As well, this central concept will allow for product and program evaluation. Such a co-ordinated program will will also allow the opportunity for professional upgrading since the field of advanced rehab technology is relatively new and products are constantly changing. This will provide more quality service delivery to the consumer.

5) There should be developed a community and rural outreach program for team members to visit people in their home, work, or school environment as specific adaptations may be required for these environments. Some people are unable to travel due to medical restrictions.

6) Augmentative communication devices should not be separated from other available technology in this proposed program. The government must consider wheelchair seating systems, Environmental Control systems, etc. in a total program since often one is reliant on the other.

7) Prior to setting up a program, the Government review similar programs already in place such as the ADP program in Ontario. Such questions as – How much money? How is it co-ordinated? Costs not only involve actual purchase of the device, but also include various therapists' fees, maintenance, inventory control, etc.

MSOT/AOTM Presentation to Government on Provision of Augmentative Communication Technology in Manitoba

The inability to use speech as a primary means of communication due to central nervous system insult, progressive disease of the nervous system or any number of other physical and psychological reasons is devastating. Persons with severe expressive communication disorders endure severe penalties educationally, socially, vocationally, and personally. It is important to realize that such a disability can affect children as well as adults. All non-speaking individuals have the right to a proper assessment and training in alternative/augmentative communication. A technical communication device is only one possible solution.

"When the word technology is used today, it usually conjures up images of space-age gadgetry. However, it is important to acknowledge the existence and value of more fundamental devices or technologies as well as technologies employing electronic devices. Most of the advanced technological aids used in rehabilitation are simply adaptations of the more fundamental approaches or aids. Moreover, many of the problems faced by disabled persons are better solved through the use of fundamental technologies rather than through advanced aids. In fact, most advanced technologies require the presence of fundamental rehabilitation technologies to be effective or even usable. For example, in the case of a person with cerebral palsy, the use of advanced technologies (e.g. an electronic augmentative communication aid) will not be effective or useful until that person's basic seating and positioning needs are addressed through fundamental seating techniques and technologies." (Vanderheiden, 1987).

Prerequisites to Augmentative Communication

There are prerequisites before augmentative communication methods can be determined. The individual must:

1) show demonstrable preferences.

2) be reinforceable by objects or events that can be represented by objects or pictures.

3) has at least one signal or mode of indication.

4) will use the signal to indicate a desire for an object or event.

5) will use the signal to indicate a choice between objects or events. (Johnson-Martin, 1987)

Such prerequisites must be carefully assessed often times involving several sessions with the individual and the caregiver. It is common that a training period occurs where these preliminary skills are used as therapeutic goals involving the individual and the caregiver.

Technology in Communication Devices

Today's communication aids vary from wooden communication boards to small portable electronic voice synthesizers. Some aids are operated by erratic pointing of a fisted hand, while others respond to very slight eye movements. Some

devices are simply a Plexiglass sheet placed in front of the user which he communicates by gazing at various letters on the board while others are much more sophisticated. Each person must be evaluated holistically to determine the most appropriate method or device for him/her.

Although it is obvious that advanced technology can help many people, it does not follow that the more advanced or higher technology always provides a better solution. In some cases electronic devices are inappropriately applied in the mistaken belief that any technology is better than no technology. Unfortunately this sometimes happens with well intentioned service groups who have purchased an expensive device for an individual only to find the device gathering dust in a closet.

Warranted use of technology

Even when a high tech communication device is warranted, it requires more than just careful selection/fitting and basic operating instruction. The user must develop special skills to gain the full benefit from these devices. This skill development requires therapy, modeling, practice, and learning new ways of doing things.

Service Delivery

Provision of augmentative communication systems should involve a multidisciplinary team of professionals working together with the consumer. The team of professionals should include occupational therapists, speech-language pathologists, and rehabilitation engineers and may involve psychologists, physical therapists, educators, technologists, and other involved professionals.

For any given individual, the provision of a communication system should involve:

1) careful assessment in terms of cognitive, linguistic, motoric and emotional capabilities, as well as the interaction of those factors

2) assessment of the environment in which the individual operates, including the characteristics of the family, the physical set up of the home and school, and the social/community milieu.

3) selection of the optimal communication system.

4) training the individual in the technical aspects of the system as well as in strategies for interacting with other people.

5) follow-up and ongoing assistance, including possible provision of adaptions to the system. (Attermeier, 1987).

It is imperative that prior to provision of an augmentative communication system, a thorough evaluation of the individual's present seating system is made. Adequate positioning (involving body alignment, adequate base of support, etc.) has been estimated to be more important than any other single factor in improving ability to use a communication system. (Mac Neela, 1987).

Role of the Occupational Therapist

The OT takes a holistic approach in assessing the individual. Occupational therapists have the knowledge of neurological dysfunction, the ability to assess motor abilities, to assess functional abilities, cognitive, sensory, and perceptual abilities, and the knowledge and skill to perform complex task analysis. The OT works in co-operation with the multidisciplinary team.

The OT is particularly involved in the assessment and provision of a therapeutic seating system. The seating system must be adapted to accommodate the communication system. Many times a new mounting system must be fabricated by the rehab engineer.

As well, the OT performs a motor assessment to determine the individual's motor skills, identification of a method that the individual can use to access the communication system, making an appropriate match between the individual's motor skills and the motoric requirements of the augmentative communication system.

The OT is involved in assessment and training of prerequisite skills (as described previously) as well as in the training program after the device is obtained. This is done in conjunction with the speech-language pathologist.

Reference List

Attermeier, S. (1987). Augmentative communication: An interdisciplinary challenge. Physical & Occupational Therapy in Pediatrics. Vol. 7, No. 2. The Hawthorne Press Inc., New York.

Johnson-Martin, N. (1987). The Prerequisites to Augmentative Communication: Their implications for therapists and early interventionists. Physical & Occupational Therapy in Pediatrics. Vol. 7, No. 2. the Hawthorne Press Inc., New York.

Mac Neela, J. (1987). An overview of therapeutic positioning for multiply-handicapped persons, including augmentative communication users. Physical & Occupational Therapy in Pediatrics. Vol. 7, No. 2. The Hawthorne Press Inc., New York.

Stowers, S., Altheide, M. R., and Shea, V. (1987). Motor Assessment for unaided and aided augmentative communication. Physical & Occupational Therapy in Pediatrics. Vol. 7, No. 2. The Hawthorne Press Inc., New York.

Vanderheiden, G. (1987). Service delivery mechanisms in rehabilitation technology. The American Journal of Occupational Therapy. Vol. 41, No. 11.

APPENDIX B

Public Forum

on

New Communications Technology

Submission by

Society for Manitobans with Disabilities Inc.

&

Rehabilitation Centre for Children

Prepared By: Art Quanbury (RCC)

Candace Plouffe (SMD)

Nigel Baseley (SMD)

1 November 1989 (Revised)

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1. Introduction

One of the most exciting and potentially rewarding developments in the field of rehabilitation services is the use of computer technology to enhance the quality of life and independence of people with disabilities. Microcomputers and other 'high-tech' products make it possible for many people with disabilities to communicate and function more independently. In fact, with appropirate technology many who are handicapped today will be independent in the future! By increasing the independence and self reliance of disabled people, these products can also substantially reduce the costs of medical, institutional, homecare and respite services.

1.1 Augmentative/Alternative Communications (AAC) Scope

Augmentative/Alternative Communication (AAC) refers to forms of communication used by persons for whom the usual forms of verbal and/or written communication are temporarily or permanently inadequate.

As such, AAC covers a very broad range of communication forms which may include the use of symbols (Bliss or pictures) to replace words, as well as signing and traditional words. Selection of the symbols or messages may be made directly in an unaided manner (e.g. pointing to symbols on a display board) or indirectly using a variety of assistive devices including, of course, computer based systems with a voice output.

1.2 Need for Service

An increasing need for an augmentative/alternative communication program is clearly recognized. For example, currently ninety preschool children have been identified by our two agencies as being non-communicative and in need of an augmentative/alternative communication system.

With increasing advances in medical technology, an increasing number of babies with severe disabilities are surviving. Medical technology is also saving individuals who have been involved in serious accidents and, as a result, the head injured population continues to increase.

Many of these individuals with severe disabilities can and are being integrated into the community. For the individuals who are non-communicative, an Augmentative/Alternative Communication System is a necessity to allow them to participate in their environment.

2. Issues

2.1 Individualization of Service Planning

A basic principle in selecting an augmentative/alternative communication system for any individual is that **the equipment should fit the person**; the person should never be made to fit the equipment.

Unfortunately, too often we see the latter happening. A person may be provided with equipment and software without a thorough evaluation of his/her individual needs, capabilities and limitations. If the equipment turns out to be not really suited to that particular person, even though it

may be capable of doing wonderful things, it can do far more harm than good.

Because of the complex nature of individuals who require an AAC system, detailed individualized assessments, program plans and intervention strategies are required to meet individual needs.

Assessment of the user's capabilities and needs, should be done by a multi-disciplinary team. For example, an occupational therapist and physical therapist are required to determine appropriate positioning of the user and the AAC equipment, and the method of accessing the equipment. A speech-language pathologist is required to determine vocabulary, and the type of AAC system (pictures, bliss, etc.) best suited to the user. An AAC facilitator may be needed to assess the user's environment to determine what type of training is needed for both the user and the individuals in the user's environment.

A well developed program plan is needed to determine the appropriate intervention strategies. The plan includes goals and objectives for the individual, the intervention personnel involved and support people needed. The user should be actively involved in developing the plan and should approve the plan before it is implemented.

Intervention strategies are the activities carried out to meet the goals and objectives defined in the program plan. For augmentative/alternative systems, intervention is a two step process – intervention is needed for the user and for the individuals in the user's environment.

The Easter Seals Communication Institute of Ontario has determined that, on average, four hundred hours of service are needed to develop a functional communication system for one individual. The process begins with the initial assessment and ends when the individual is able to use the communication system successfully in his/her own environment. These four hundred hours include many professional hours (from a variety of disciplines) for programming. The **provision of equipment is only one aspect** of the total program.

2.2 Degree of Coordination

It is universally recognized and accepted that the effective provision of an AAC service requires a multi-disciplinary team including speech/language pathologists, occupational and physical therapists, rehabilitation engineers or technologists, special education teachers, social workers and others.

Because of the need to have a multi-disciplinary team that can work closely together, a high level of coordination of AAC service is necessary. At the same time AAC is very much an environment dependent activity and a close working relationship with local caregivers and service providers is necessary for the provision of a suitable system.

2.3 Universality

The ability to communicate should be treated as an individual's right, not a privilege. For this reason augmentative/alternative communication

programs need to be developed to ensure that individuals with communication impairments have this right.

The type of communication system can vary, incorporating low or high technology. For some individuals use of an electronic communication equipment is the **only** option, for others this may be one of many options. The ability to have access to a wide range of equipment (including expensive high technology equipment) needs to be considered in terms of financial implications for the system.

2.4 Training

Training, both initial and ongoing, and at several levels, is a necessary component of an AAC service program.

Initially, the members of the professional team must receive training in AAC service delivery aspects (assessment, evaluation, implementation and follow-up). The user of an AAC system requires an initial period of intensive training followed by long term training as his/her communication skills and requirements change. A 'facilitator', someone close to the user, must receive training in the specific AAC system so that the user's system can be changed or modified frequently to reflect changes in use.

2.5 Support Services

The initial purchase of AAC equipment is perhaps the simplest and most straight forward part of an equipment provision program. Even the simplest equipment requires periodic maintenance and more complex equipment may require service contracts to control maintenance expenses and the provision of back up or 'loaner' systems. Maintenance may include a combination of local and dealer involvement. An AAC system is a growing, dynamic one – changing as the communication needs of the user change. Through the follow-up process needed modifications to the system can be identified to allow such items as new and expanded vocabulary, different communication functions (e.g. the need to communicate to a group rather than to one individual) and perhaps modified or completely different forms of access. These are generally 'labour intensive' modifications that will require an individual's time rather than the purchase of a new item of equipment.

3. Role of SMD and RCC

In light of their respective mandates and the needs of the people they serve, both the Society for Manitobans with Disabilities Inc. and the Rehabilitation Centre for Children have been involved in some aspects of AAC Service delivery.

The Society provides a wide range of services to a clientele of over 12,000 people with disabilities. The people served range in age from birth to 65 and they exhibit a wide variety of disabilities.

The RCC provides a range of different, but complementary, services which are available to all children in Manitoba with physical disabilities.

A significant number of the clientele of both agencies are affected by communication impairments.

Both agencies have for a number of years recognized the considerable benefits that can be gained by many people with disabilities from the use of computers and adaptive devices. The two agencies are building expertise in the use of such technology among their staff of speech pathologists, occupational and physical therapists, biomedical engineers, psychologists, teachers and social workers.

For example, the Society has for the past three years been testing and demonstrating the uses of micro-computers and related devices in its services to preschoolers with disabilities. It has been doing so in collaboration with the Early Childhood Development Centre of the University of Western Illinois (a world leader in the use of computer technology in the field of early childhood development and education).

For the past three years the Society has also been using a specialized computer-based vocational evaluation system. It is experimenting with the use of computers in its tutoring program for deaf and hearing impaired adults. It is also in the process of implementing a Management Information System development project, utilizing over 30 computer workstations. This project will be used as a vehicle to test specialized office automation software and adaptive devices which can be used in the workplace by people with disabilities.

The Rehabilitation Centre for Children has special workshop facilities and technical expertise to provide equipment for seating, positioning and mobility of children with disabilities, plus prosthetic and orthotic devices (including myo-electric prosthesis).

The RCC provides special equipment for the control of electronic equipment, including electric wheelchairs, environmental control systems, alternative and augmentative communications equipment and computer equipment.

Both the Society and the RCC recognize the particular importance of Augmentative and Alternative Communication technology for people with communication impairments. In view of this and also in view of their complementary services, and limited resources, the two agencies began collaborating at the end of 1987 to develop a joint AAC services project.

A proposal, focussing on the needs of preschool children in rural areas was submitted to the Federal Government for funding in 1988. We are still awaiting a final decision on this proposal.

4. Recommendations

4.1 Collaboration between Government Departments

We recommend that the Departments of Family Services, Health and Education and Training work closely together to develop policies and a funding mechanism for AAC initiatives.

4.2 Holistic System Approach

We recommend that the government develops policies and funding procedures that incorporate both the equipment aspect of augmentative/alternative communication systems as well as the programming related needs (Individual assessment, Program Plan, Intervention Strategies).

Policies and procedures should also provide for continued follow-up/adjustment to the AAC systems provided to individuals.

4.3 Coordination

There are already a number of service providers, associated with various agencies and including various teams of professionals, providing some AAC service to a variety of user groups. This activity needs to be coordinated to take advantage of existing experience and to strengthen the overall provision of AAC services.

It is important to identify and build on the strengths of the present service systems and not introduce initiatives which result in further fragmentation.

4.4 Balanced Funding

There needs to be a balance between any funding for equipment and funding for staff and facilities to support the other components of a service program including evaluation, assessment, training, follow-up.

4.5 Equity

It is important that any Government initiatives include the needs of people with communication impairments who live in the rural regions of the province as well as those who live in Winnipeg.

APPENDIX C

The Manitoba Speech and Hearing Association

Kiwanis Centre of the Deaf
313 - 285 Pembina Hwy., Winnipeg, MB R3L 2E1 — Telephone (204) 453-4539

November 14, 1989

Mr. Jim Derkson, Co-ordinator
Decade of Disabled Persons
470 – 125 Garry Street
Winnipeg, Manitoba
R3C 3P2

Dear Mr. Derkson:

Please find enclosed a transcription of The Manitoba Speech and Hearing Association's presentation at the public forum on augmentative communication devices November 1, 1989.

We thank you for the opportunity to participate in the forum and we would be happy to participate in any following activity which the Government of Manitoba may plan.

Yours sincerely,

Margaret Ellis
Speech-Language Pathologist

ME/EC
enc.

cc. Mrs Adair Morrison
President
The Manitoba Speech and Hearing Association

The Manitoba Speech and Hearing Association

Kiwanis Centre of the Deaf
313 - 285 Pembina Hwy., Winnipeg, MB R3L 2E1 — Telephone (204) 453-4539

The Manitoba Speech and Hearing Association

Presentation at the Public Forum on Augmentative Communication Technology

Sponsored By
The Decade of Disabled Persons Initiative

November 1, 1989

The Manitoba Speech and Hearing Association compliments Mr. Jim Derkson and The Decade of Disabled Persons Initiative for organizing this public forum on augmentative communication devices.

The Manitoba Speech and Hearing Association is the professional association of speech-language pathologists and audiologists.

In our experience an augmentative communication device can be an incredibly beneficial aid to non-speaking people. It may enable a person to communicate with family, institutional caregivers, to socialize in the community, to participate in classroom discussion and to address groups such as this. This can be described as liberating for the person who, without the aid, can communicate with nobody or, as is more often the case, can communicate with only one person at a time in face to face interaction and even then, only with those who are familiar with his communication system. Further, augmentative communication devices often have utilities for printing notes, letters, homework assignments, controlling appliances such as the television, and accessing all the benefits of the computer.

Augmentative communication devices are high technology. They are expensive. At the present time Manitoba has very little public policy in terms of their prescription and in terms of their funding. When the support team working on behalf of a nonverbal client wants to try out an augmentative communication device or to purchase one it must start hunting for funding. We try Manitoba Education and Training which will provide peripherals and software for as long as a child is in school, but will not purchase the augmentative communication device. We try Income Security, we try our employing agencies. Parents have tried through their medical benefits of their employing agencies. We try through Autopac settlements and through Manitoba Health Services Commission. We go to service clubs for funding. Funding for these devices is very difficult to obtain.

It becomes particularly difficult when the support team isn't sure whether any device, or this particular device, is going to be useful. There are eventualities which are difficult to predict. The adolescent may reject a device because he doesn't want anything which may make him look different from his peers. The nonverbal adult may reject the device because the synthesized speech sounds too unnatural to him. Often we are unsure whether a device is appropriate to the client's needs. Therefore we want to utilize the device on a trial basis. Cost of renting such complex equipment may run to $300.00 a week.

Public policy regarding the prescription and funding of augmentative communication devices is needed. The provinces of Ontario and Alberta have instituted policy and programs which may provide models of service and funding which could be of assistance in formulating Manitoba's policy and programs.

The issues surrounding augmentative communication devices are much more complex than just funding concerns. The question of funding immediately triggers the questions of: What are the qualifying criteria? How can we assure that dollars are being well spent? How can we build into the system quality

assurance? How can we be best assured that the interests of the nonverbal person are being protected?

1. We must ensure that the support team working on behalf of the nonverbal person can provide for all aspects of augmentative communication.

   Is someone addressing the issues of how the nonverbal person will be positioned; how a wheelchair can be modified; how the person will control the device; how he will develop the motor skills necessary; is he cognitively ready?

   Who will counsel the caregivers; who will figure out what types of symbols will be used (letters, words, Blissymbols, pictures); how will the person's communication needs be assessed; who will take responsibility for modifications to the environment.

   Has a developmental training program been in place prior to prescribing the augmentative communication device; who will ensure the client has input into its utility; who will fix it when it breaks down; is there a back-up system when it breaks down?

   The answer is, of course, no one person can assume responsibility for all the issues. The support team, depending on client needs, consists of occupational therapist, rehabilitation engineer, speech-language pathologist, physiotherapist, parents, teachers, behaviour specialists, institutional caregivers, and the nonverbal person himself. The success of augmentative communication, whether requiring little technology or requiring a highly technical device, in large part, depends on the strength of that interdisciplinary team.

   In Manitoba we have places where such teams are already functioning, and we have places where only some members of the support team are available. Centres where the appropriate support team is in place, or is partially in place, are schools, hospitals, rehabilitation centres, and day-care programs.

2. We must ensure that the augmentative communication device is the one which supplies the best potential to the nonverbal person. There are approximately 300 new devices, peripherals and software on the market every year. It is very difficult for us to keep abreast of more than a small portion of the development in technology and software.

   "Clinicians who recommend systems based only on their own knowledge of available systems necessarily do so based upon incomplete information, with the assured result that less than optimal recommendations will sometimes occur. Clients in these situations will be offered less from their systems than they could have been offered, resulting in lower communication performance, decreased development of their skills for which communication is necessary, and overall decreased quality of life." (Woltosz, 1988)

   Woltosz (1988) suggested that the support team develop a description of an ideal augmentative communication device for the individual. That is, based upon the team's assessment, describe a generic device to fit the person's

needs and put this description out to tender to the manufacturers or their representatives. These companies know their devices and would respond with the information on the device they have available which best fits that individual's needs. This process may appear to delay the acquisition of the device. However, it would certainly assist in avoiding the error of fitting an inadequate device to the nonverbal person's needs, which can happen if we rely on manufacturer's catalogues or on the knowledge of a device seen at a display at a convention or forum such as this.

3. Manitoba has no adequate needs study. We know that only a small percentage of nonverbal people can or will utilize augmentative communication devices. We know that the improper supplying of a device, at the improper time in the individual's life can actually do harm. Experience with a useless device, improper for the person's presentabilities, is very frustrating and disappointing to the nonverbal person who may have had his expectations built up. Such practice is unethical. It may result in rejection of the very idea at a future date, when proper training is available, or when a better device is found, or when the abilities and life situation of the nonverbal person make it more usefull.

   Needs studies, with strict adherence to guidelines of utility to the person, are needed.

4. We must ensure that adequate training programs are in place. Training programs must avoid the classic situation where the person only uses augmentative communication with the speech-language pathologist or occupational therapist, or only relays a few taught messages, or never initiates messages. That means that training programs must begin long before the acquisition of an augmentative communication device _ sometimes years. Training should take place in the same situation the device is going to be used. Parents, caregivers, teachers, hospital personnel, day programs, group homes, vocational settings must be involved in the communication program. Conversation partners must be counselled not only for acceptance, but in facilitation techniques for communication. Goals should be developed from the communication needs of the nonverbal person in all his activities of daily living. The speech-language pathologist can assist in defining the person's communication needs: where does communication break down; what idiosyncratic systems are presently in place; and what can we do to facilitate communication?

   The Manitoba Speech and Hearing Association has just touched upon some of the concerns and issues in the field of augmentative communication. The benefits of developing funding policies which contain criteria for prescribing augmentative communication devices is that such policy could be a vehicle for ensuring that the interests of the non-speaking population are addressed.

   In summary, The Manitoba Speech and Hearing Association is advocating that our government develop policy and programs regarding augmentative communicative devices, and that the process include representatives from the nonverbal population, advocacy groups, parents, professional associations and the various government departments who are involved in serving the nonverbal population.

Reference:

Woltosz, Walter, (1988). A Proposed Model for Augmentative and Alternative Communication Evaluation and Selection System. **Augmentative and Alternative Communication**, VOL. 4, DECEMBER, 233-235.

APPENDIX D

Right to speak stressed at forum

by David Martin

Imagine what it would be like if the Manitoba government had never decided to fund a wheelchair services program through the Society for Manitobans with Disabilities. Individuals with mobility impairments would face the prospect of not being able to move. Imagine applying for a job if you couldn't move and didn't have a wheelchair.

Fortunately, however, this scenario was addressed in our province in the early 1970s with the introduction of a universal program to provide basic mobility aids at no cost to any Manitoban in need.

Unfortunately, meeting the needs of people with speech impairments is a different story. There is not a program to provide speech aids to people who cannot speak. Imagine applying for a job if you couldn't tell your prospective employer about your qualifications.

Questions like these were asked at the first of a new round of Consultative Forums sponsored by the provincial government's Decade of Disabled Persons initiative. The Forum took place in Winnipeg on November 1st with about 50 people in attendance. During the Forum, presentations were made by speech therapy groups, consumer groups representing people with disabilities and occupational therapy groups.

As the presentations unfolded, it quickly became apparent that two visions were being promoted. Groups representing speech and occupational therapists urged that the government establish a speech enhancement program and that professionals be heavily involved in the evaluation and selection of different equipment.

Consumer representatives also recommended that a program be developed, but they argued that the speech impaired person should maintain ultimate control over the choices they make concerning which equipment meets their needs.

While the two views are not mutually exclusive, a real difference of emphasis emerged during the Forum. In many ways, it can best be described as a classic example of the ongoing discussion about the appropriate role, and level of involvement, of consumers and professionals in the delivery of a program for people with disabilities (in this case a speech enhancement program).

Of course, the debate is somewhat academic on this subject until the government decides whether such a program will exist. On the need for such a program, all agreed the time had come.